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Beyond the diagnosis: Experiences of Persons living with Hepatitis B infection in the Accra Metropolis of Ghana

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Beyond the diagnosis: Experiences of Persons living with Hepatitis B infection in the Accra Metropolis of Ghana

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ABSTRACT

Objective: This study explored the psychosocial experiences of hepatitis B chronically infected individuals in the Accra metropolis.

Design: The study employed qualitative exploratory descriptive design with purposive sampling technique. Data were collected through face-to-face interview and transcribed verbatim. The data were analysed using content analysis.

Settings: Two hospitals including one government and one mission hospital in Ghana were used as data collection sites.

Participants: Fourteen (14) individuals living with hepatitis B infection for one year and above were interviewed.

Results: The findings of the study showed that people living with HBV infection in Accra metropolis lacked awareness about HBV infection and also experienced psychological and social problems especially during the early stages of their diagnosis. Few among them include sadness, worries, fear, shock, shame, and disbelief. Coping strategies adopted by participants include religiosity, diversional coping strategy and lifestyle modification.

Conclusions: It is therefore necessary as a country to integrate hepatitis B counseling into the already existing HIV structures in the health delivery system in Ghana to offer support for individuals diagnosed with HBV infection.

Key Words: Experience, Ghana, Hepatitis B, Infection

Strengths and limitations of this study

- This is the first study to explore the experiences of people living with hepatitis B infection in Ghana.
- Sadness, worries, fear, shock, shame, and disbelief characterise diagnosis of hepatitis B infection in Ghana.
- Different coping strategies including religiosity, diversional approach and lifestyle modification are used by persons infected with hepatitis B infection to maintain their quality of life.
- This suggest the need to provide care and psychological support for individuals diagnosed with hepatitis B infection
- A study on hepatitis B related stigma in the study setting will be appropriate.

INTRODUCTION

Hepatitis B virus (HBV) infection remains one of the most important public health concerns worldwide. According to the World Health Organisation (WHO), an estimated two billion people have evidence of present and past infection of HBV globally, and more than 240 million are chronic carriers of the virus.¹ In 2010, HBV infection was found to be the tenth leading cause of global deaths and about 50% of deaths as a result of liver cancer were attributed to HBV infection.^{2 3} The consequences of HBV infection such as liver cirrhosis, hepatic failure and hepatocellular carcinoma are well documented to cause approximately 780,000 deaths annually on a global scale.^{2 4 5}

Even though no global estimate of economic impact of HBV infection was found, it is well documented that hepatitis B imposes a huge economic burden on patients, families, health system and the society at large spanning from health care cost, cost of treatment and work loss.^{6 7 8} For instance, a study done in Vietnam showed that the total cost of treatment of hepatitis B infection and its complication was estimated to be US \$ 4.4 million nationally and the patient suffers a huge cost of care when the condition becomes more severe.⁸

Currently, HBV infection is receiving international recognition and attention from WHO and the World Health Assembly with recent emphasis on four axes; raising awareness, promoting partnership and mobilising resources, developing evidenced-based policy, prevention of transmission and increasing access to care, treatment and support.⁹ This attention is demonstrated by the coming into being of the first WHO guideline for prevention, care and treatment of persons living with HBV infection.¹⁰

Ghana is endemic with HBV infection with about 8% to 20% of the adult population estimated to be living with the disease.^{11 12} Furthermore, the long term consequences of HBV infection are also reported to account for 42.9% (n=70) of liver cirrhosis in the country.¹³

Global evidence indicates that, living with HBV infection is associated with social and psychological afflictions such as stigma, discrimination, anxiety and depression.^{14 15 16 17 18 19} However, in spite of the high prevalence (i.e. 8-20%) of HBV infection in Ghana, no

study was identified by the researchers that sought to explore the experiences of persons living with HBV infection. Therefore, the purpose of this study was to explore the experiences of people living with HBV infection in the Accra Metropolis, Ghana.

METHODS

Study design

Qualitative exploratory descriptive design was used. This design was appropriate because according to Grove, Burn and Grays²³, an individual experience is unique to him/ her and can be in the best position to give an account and meanings to their own experiences.

Study Setting

The study was conducted in the Greater Accra region of Ghana. The region is one of the ten administrative regions in Ghana. Notwithstanding, it is the smallest of the regions and occupies a total land area of 3245.²⁴ Greater Accra region is found in the South-Central part of Ghana and shares borders with the Eastern region to the north, Central region to the west, Volta region to the east and the Gulf of Guinea to the south.²⁴ According to the 2010 population and housing census, about 4,010,050 people resides in the region.²⁴ One Mission hospital and one government hospital in the Accra metropolis were used as data collection outlets.

Participant's eligibility

Inclusion Criteria

Participants were included in the study if they were between the ages of 25 years and 45 years and have tested HBsAg positive for a period of six (6) months or more and consented to participate in the study.

Exclusion Criteria

People living with hepatitis B who were not emotionally stable were excluded from the study.

Sample and Sampling Method

Purposive sampling technique was employed to select individuals living with HBV infection who met the inclusion criteria. A purposive sampling technique is a non-probability sampling method in which a researcher selects participants based on the inclusion criteria and purpose of the study. In this case, the researchers were interested in informants who were willing to give information by virtue of their experience.²⁵ This was however appropriate for this study because it helped the researchers to gain an insight into a new area and understood complex experiences.²³

Sampling Size Determination

Fourteen (14) participants were recruited even though data were saturated at the eleven (11) participant's. Data collection continued despite saturation to determine if new issues will emerge. Data saturation is the point at which no new information is obtained during an interview.²²

Data Collection Tool

In-depth interview was used. This was achieved by using semi-structured interview guide to collect data from each participant. The guide had both open and close ended questions which allowed the researchers to probe until in-depth information was obtained from each

participant. The guide was designed based on the study objectives and literature. Additionally, field note was taken during the interview session.

Data Collection Procedure

Participants' recruitment commenced after ethical clearance was obtained from Institutional Review Board of Noguchi Memorial Institute for Medical Research of the University of Ghana. Also, permission from the management of the data collection outlets were obtained. The purpose of the study was explained in detail to the participants to get their cooperation doing the recruitment session. Participants who agreed to take part in the study were given a consent form to sign as an indication of their willingness to be part. A convenient time and venue for each participant was arranged after they had consented to participate in the study. Furthermore, consent of each participant was sought to record the interview session using audio-tape recorder after its rationale of record keeping for reference purpose has been explained to them. Data were collected between January and February 2016 mostly in the homes of the participants. Each interview lasted between 45 and 60 minutes. Data collection was halted when participants expressed a feeling of apprehension when recounting their experience and counselling was offered to those who were emotionally disturbed during the interview.

Data Analysis

Data were analysed using content analysis technique. The researchers played and listened to the audio-taped interviews and transcribed verbatim to familiarise themselves with the data. The researchers coded the data individually, followed by series of group discussions of the codes and the generation of the major themes. The researchers however ensured that there were linkages between the themes and the codes. Sub-themes were created from the themes and the study findings are presented using the themes and the sub-themes.

Methodological Rigour (Trustworthiness)

Trustworthiness can be achieved by establishing credibility, transferability, dependability and confirmability.²⁶ This current study took into consideration all the aforementioned rigour in qualitative study. Credibility was achieved by piloting the interview guide using two participants from a referral hospital in Accra. Member checking was done concurrently with data collection. Additionally, all data collected including recorded voices, transcription, field diaries were compiled into an audit trail. Transferability was ensured through a detailed description of the context in which the study was carried out. The research setting, sample and sampling technique and data collected from participants are reported in detail. More so, rich and accurate quotations of participant's response were quoted verbatim in this study. To ensure dependability, all field notes, transcription and voice recorded are kept in an audit trail. Furthermore, the researchers ensured confirmability by keeping audit trail.

RESULTS

Demographic Characteristics

The study recruited a total of fourteen (14) hepatitis B infected persons. Participants were within the age range of 26 years to 45 years. Seven of the participants had tertiary level education, five had primary level education with only two having no formal education. Two participants were single, three divorced after being tested hepatitis B positive and the remaining nine were still married. Females were eleven with only three males. The participants have been living with the infection for a period of one to five years. None of the participants was on prescribed treatment. Pseudonyms were used to ensure anonymity of participants.

Individual Level Factors

This theme describes the individual level factors that influence one’s social and psychological experiences. The study revealed that, persons living with HBV infection suffer some degree of psychological challenges including sadness, worries, fear, shock, shame, and disbelief. Furthermore, lack of awareness of the disease and blame was noted among some study participants.

Lack of Awareness

The findings showed that some participants were not aware of HBV infection before they were diagnosed positive. Moreover, those who were aware had some knowledge gap about the infection. Some participants admitted their ignorance but others classified the population in general to be deficient of hepatitis B related information as compare to HIV which is known by many.

“As for hepatitis B, I didn’t know about it until I got infected. What I knew to be deadly is HIV. It was the laboratory man who educated me about the disease that it is also dangerous”
[Sozo]

“As for HIV we all know about it but this hepatitis B, it is new to us. I only heard of it on radio but I don’t really know what it was” [Momo]

Sadness/ Worries /Fear

Most participants reported that they were sad, worried and scared about their HBV positivity. According to them, this psychological trauma was more visible during the early stages of their diagnosis. More so, participants who were aware of hepatitis B infection and its associated complications manifested more of these symptoms.

“Because I have heard about the seriousness of the disease on radio, I felt so scared and worried. Infact, I started sweating and suddenly became weak in my bones. Fear gripped me so badly that my whole day was spoilt. I was scared until I went on the internet to read about it then I realised it is not as dangerous as HIV as said on radio. It was after knowing that I became a bit relaxed” [Kim]

Participants who knew someone who has died of the disease were very much terrified when they got to know their status.

“My friend was told that she has hepatitis B about five years ago. She then started falling ill more often and finally died last year. So when I was told I was hepatitis B positive, I was extremely scared by the result” [Maju]

The major driver of the psychological affliction associated with the infection is the comparison of the disease with Human Immuno-deficiency Virus (HIV). Most participants perceived HBV infection to be more dangerous than HIV and therefore felt their life will soon come to an end.

“I think the sadness is a normal feeling because some say the disease is more dangerous than HIV so it means that you have a short life. You can die at anytime. That makes me sad. I think about my children. What will happen to them if I die and leave them behind?These are the things I think about” [Hani]

1
2
3 *"You know, some people say on radio that hepatitis B is more serious than HIV and I know*
4 *how people with HIV end up to become. So I was imagining myself being in a worst situation*
5 *than someone with HIV.....Also, the liver is only one so if it gets spoilt then that means my life*
6 *will finish"* [Kim]
7

8
9 Some participants reported that hepatitis B adverts on radio and television particularly those
10 presented by herbal medicine practitioners did fuel their fear.

11 *"I only think about it (hepatitis B) when I see an advert on television.... Because the way they*
12 *describe it as very dangerous, I become so scared, especially the herbal medicine sellers.*
13 *They sound so scary as if you will die tomorrow when infected. At that moment, I become so*
14 *afraid but as soon as it is over then I become fine."* [Maju]
15
16

17 18 **Shock /Shame/ Disbelief** 19

20 The study found that, disclosure of HBV status to some of the participants came as a shock to
21 them as they never anticipated the possibility of positive result. This according to the
22 participants occurred because they were not prepared at the time of diagnosis to receive a
23 positive test result. Some participants revealed that they got tested for hepatitis B because per
24 the policy of the hospital they attended for delivery, every pregnant woman was mandated to
25 have HBV screening before delivery.
26

27 *"Well...I felt very bad and was thinking otherwise like how come I am having this virus*
28 *I was really shocked!"* [Yoland (Divorcee)]
29
30

31 According to Hani, knowing that she was hepatitis B positive was the greatest surprise in her
32 life. She indicated that her sense of dignity was lost when she got to know her positive status.
33 She lamented:
34

35 *Hmmmm! I could not believe it. I was more than confident before the testing that I will be*
36 *negative. Because growing up as a young lady, I never involved in any bad practices such as*
37 *sleeping with men. I remained a virgin till I married my husband so I have never thought of*
38 *being positive. I really felt ashamed and shocked!* [Hani]
39
40

41 The effects of participants' bitter experiences were noted to affect their job since mental
42 distortion were reported. This was much pronounced in a situation whereby participants were
43 not able to vividly establish the cause of their infection.
44

45 *"Sometimes, I lose concentration even at work. Especially when I remember that I am*
46 *hepatitis B positive. I sometimes think to see if I can pin point the main means that*
47 *I got the disease. That alone put me into psychological stress"*[Hani]
48
49

50 51 **Blame** 52

53 Majority of the female participants did not hesitate to link their infection to their spouse's.
54 According to most of them, their spouses indulge in extra marital affairs and therefore might
55 have gotten themselves infected through their multi-sexual behaviours. Some even inquired
56 from the health care providers to ascertain such possibilities. Maju narrated:
57
58
59
60

1
2
3 *"I first asked the nurses if my husband might be the one who has given to me but was told not*
4 *really because there are so many ways I can get it" [Maju]*

5
6 Furthermore, participants who perceived their partners to be unfaithful in their marriage
7 confidently attributed their source of infection to them. This is well said in the two quotes by
8 Yoland and Maju below:
9

10 *.....I was putting the blame on my husband. I suspected him because when I was with him, he*
11 *was always flirting with other ladies [Yoland (divorcee)]*

12
13 *I have seen him (husband) many times with other women so I will not be surprise if he is the*
14 *one giving me this dangerous disease. He does not live a clean life. What I mean is that he*
15 *likes chasing girls [Maju]*

16
17
18 On the other hand, some of the participants resorted to blame as a strategy to let their spouses
19 go for hepatitis B test. This was more common among women who suspected their partners to
20 be promiscuous. Yoland and Hani recounted what they said to their husbands:
21

22 *"I said....You (spouse) need to go for check-up so that we know where it is coming from...*
23 *whether from you or not?"[Yoland]*

24
25 *"I only wanted to be sure if my husband is not the one who has given me the disease.*
26 *So I told him to go for the test so that we all understand why?" [Hani]*

27
28
29 Sozo reported how she finds it difficult to forgive her mother after she got to know of her
30 positive status. According to her, she could have prevented herself from being positive when
31 she tested negative during hepatitis B screening at school. But because her parent failed to
32 recognise the significance of hepatitis B vaccination and therefore refused to pay for it, she is
33 now positive five years down the line. She lamented:
34

35
36 *"Hmmm! My story is different. I could have prevented myself from this disease. About five*
37 *years ago I had the test and was negative. By then I was in school so I called my mum to*
38 *inform her about the cost of vaccination but she said no. That is why I feel that she is the*
39 *cause of my own"[Sozo]*

40
41 **Coping strategies**

42 Some of the participants were affected by the diagnosis and therefore resorted to different
43 approaches to cope with it. Others had superstitious belief that they are bewitched by
44 someone and that explains why they are HBV positive. Revelations by some spiritual leaders
45 made others to accept the contribution of spirituality to the cause of the disease.
46 Notwithstanding, some participants accepted the disease as a normal occurrence.
47

48
49 **Religiosity**

50 Religion plays an important role in the life of people as it shapes one's ideology and
51 perception about events. For many, God is the determinant of a person's destiny and therefore
52 whatever comes their way are the plans of God concerning their life. This assertion by most
53 of the participants made them to believe God for healing and therefore prayed with the hope
54 that they will be healed one day.
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3 *"The day I was informed that I have this disease, all what I said was my enemies had raised*
4 *a war against me. I went on my knees and prayed that the Lord should deal with them*
5 *because He is the only one who can fight my battle for me"* [Kuku]
6

7 *"As for me, I am only depending on God for my healing. Sometimes, I go for a Bible and start*
8 *reading. I do that because I believe God has the power to heal all diseases"* [Maju]
9

10
11 Some participants depended on words of encouragement from their spiritual leaders to cope
12 with the disease. Yoland shares how her engagement with her pastor calmed her down.

13 *"It didn't affect me because we were having our pastor so we informed him. He prayed about*
14 *it and he said the second test shouldn't be positive. I didn't talk about it again and didn't*
15 *want to put it in my mind that I have this hepatitis B but just to think about my baby"*
16 [Yoland]
17

20 21 **Diversional Approach**

22 Different people have various ways of dealing with chronic conditions. The study revealed
23 that majority of participants take off their minds from the disease as a means of coping with
24 it. This was noted as a strategy by many to overcome the stresses associated with the
25 condition.
26

27 *"I take it as normal. I don't think about it. I move my life freely. I did not put it in my mind so*
28 *it doesn't move me to sit down and think about it"* [Momo]
29

30
31 *"I just brushed it off and not to think about it that I have hepatitis B. The more you put it in*
32 *your mind, the more you can't even move on in life"* [Yoland]
33

34 Maju also indicated that she has tried not to listen to or watch programmes about hepatitis B
35 because it causes her to think about the disease.
36

37 *"When the advert comes, I take my mind off it"* [Maju]
38

39 **Lifestyle modification**

40 Some participants changed their lifestyle after the diagnosis. This according to them was an
41 attempt to prevent developing serious complications. Intake of alcohol and fatty foods were
42 avoided by many.

43 *"Before I got to know I was hepatitis B, I was drinking a lot of alcohol; I mean hard ones like*
44 *"Akpeteshie" (local gin). After knowing, I stopped because the nurse said what can kill me is*
45 *the alcohol since it helps to destroy the liver fast. This made me to be afraid and I stopped*
46 *drinking the alcohol. I now feel ok because I know that I will live a longer life"* [Sozo]
47
48

49 Kora also shared how she has modified her lifestyle after receiving education on hepatitis B
50 from a resourced person. She now strictly adheres to foods that are recommended for persons
51 living with hepatitis B infection. She had this to say:
52

53 *"Luckily for me, where I attend church, i.e. our church mother (pastor's wife). she has a little*
54 *background of medicine....so she always talks about the hepatitis B. She has been teaching us*
55 *how to live if you have it, the food you have to eat and that kind of stuff. So that is what I*
56 *depend on"* [Kora]
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Furthermore, the study found that, some lifestyle changes were a bit of worry to some of the participants. They perceived it as a burden because they have to live with the condition for the rest of their lives.

“Yes it does because sometimes when you go out with friends there are things you cannot do. You cannot take alcohol, there are foods you don’t have to eat then is like restricting yourself from so many things”

DISCUSSION

In this study, HBV chronically infected persons demonstrated limited level of awareness of HBV infection with some knowledge deficit about the disease before diagnosis. Similar findings are reported in several studies in other countries.^{27 28 29 30 31} For example, Dahl et al.²⁷ found that 50% (N=55) of HBV chronically infected persons selected in three hospitals in Australia mentioned kissing and mosquito bites as sources of HBV mode of transmission. Interestingly, most participants in this present study were more familiar with HIV infection than HBV as shown by their frequent reference to HIV as a more dangerous and well known disease than HBV. Perhaps, the high campaign programmes carried out over the years about HIV might be the reason underlying this revelation. However, this is not surprising since the recent Ghana demographic and health survey report indicates 96% HIV awareness level among the populace.³² For many of the participants in this study, they became aware of HBV after their diagnosis. This is consistent with a study finding by Rafique et al.³⁷ in Pakistan which reported that participants were unaware of HBV infection until they tested HBV positive. In addition, the low HBV awareness and knowledge level of the participants may also be due to fewer HBV programmes and awareness campaigns in most communities in Ghana as reported by Nkandawire et al.³³ in the Northern part of the country. This therefore suggests a huge hepatitis B response gap particularly in improving the awareness and knowledge of the disease in the general population including those living with the infection.

Furthermore, health professionals are documented to be the main source of HBV information to individuals³⁴ but surprisingly, many study findings have shown inadequacy with respect to their knowledge regarding HBV infection^{35 36} which obviously have an implication on information passed onto the consumers of their expertise. A particular example is a study finding by Chao et al.³⁶ which revealed that about 34% of health professionals failed to recognise that chronic HBV infection is usually asymptomatic and could not identify all the modes of HBV transmission. Many factors account for this gap in knowledge among this critical staff. One of these factors may include lack of capacity building of these important agents to equip them with current evidence of HBV infection. This was noted by a study conducted by Adjei et al.³⁵ in the Eastern region of Ghana which revealed that 49.2% of physicians and midwives in the study area had never attended any workshop on HBV infection after their formal training. Undoubtedly, this may have negative consequences on their practice including management, care and support of people living with this infection.

Consistent with other studies in Asia, Malaysia and Australia,^{20 21 37 38} the current study found that most participants were sad, worried and entertained some fears when they got to know their HBV positive status. This was partly due to the fact that participants were not very much prepared for positive HBsAg outcome before the diagnosis. It is worth mentioning that there are no clear guidelines on management of HBV infection in many health facilities in Ghana and therefore information about what to do next after positive HBsAg result is not well communicated to clients including follow up care. This among other things leaves the

infected person in a state of confusion after diagnosis. This finding is in line with a study in Malaysia.²¹ Perhaps, the non-existence of pre-test and post HBV test counselling reported by the participants made those who tested positive to live with the myths about HBV infection that they already knew.

Furthermore, it was found that majority of the participants interviewed expressed fear and worry about their HBV positivity and this was more pronounced among those who were very much aware of the complications associated with the infection such as liver cancer, and cirrhosis. In support of this finding, a study done in Malaysia documented that positive HBV infected persons with some knowledge about the consequences of their positive results expressed more fears as compared to those with inadequate knowledge.²¹ This psychological distress has been attributed to the fact that HBV infected persons consider themselves as possible sources of infection to their family and friends.^{20 37} This suggests the need to draw lessons from HIV guidelines regarding post-test counselling by trained health personnel to ameliorate this burden that HBV chronically infected persons experience after diagnosis.

According to this current study, hepatitis B infected persons experienced shock, disbelief and shame of their positive HBsAg status particularly during the early stages of their diagnosis. This corroborates with other related study findings.^{21 31} However, the reaction of the current study participants could be largely due to the fact that the testing was not voluntary for many but rather as part of the health facility protocol for every pregnant woman and therefore participants had no choice but to comply. Even though the intention to avert mother to child transmission is good, it is equally important to also consider the psychosocial burden that those who may test positive will experience for appropriate intervention in that regard. Moreover, because people who are HBV positive are unable to point out the source of their infection,^{28 37} it can therefore be speculated to be one of the reasons which account for the shock and disbelief that characterises the disease diagnosis. The end result of this experience has the tendency of exposing HBV chronically infected person more to a state of depression and anxiety.^{14 15}

Study Limitation

The strength of this study is that, to the best of the researchers knowledge, it is the first study that explores the experiences of persons living with hepatitis B in Ghana and Africa. However, the qualitative design employed for this study makes the finding not generalizable to the entire people living with HBV in Ghana. Notwithstanding, a context with similar characteristics can employ transferability as used in qualitative study approach.

Conclusion

The outcome of the study showed clear psychological and social challenges that HBV infected persons experienced right from the time of diagnosis throughout their life. It therefore suggests a more public health intervention that can critically respond appropriately to this burden currently confronting many people in Ghana specifically in care and support. We therefore recommend integration of hepatitis B counselling in the already existing HIV structures. Furthermore, hepatitis B infected individuals should be offered post-test counselling after diagnosis to help allay their anxiety and fear.

Abbreviation

HBV- Hepatitis B Virus; WHO-World Health Organisation

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Availability of data and materials

Transcribed data cannot be shared since participants did not consent to this. However, they are with the authors to avoid possible identification of the quotations with any of the participants.

Authors Contributions

CAA conceptualised the study. CAA, FN, ESD designed the study and the interview guide. Data were collected by CAA. Data analysis was done by FN, ESD and CAA. Manuscript was critically reviewed by FN and ESD. All authors read and approved the final manuscript.

Competing Interest

The authors declare no competing interest

Consent for publication

Not applicable

Ethical Approval

Ethical clearance was obtained from Institutional Review Board of Noguchi Memorial Institute for Medical Research (Approval number NMIMR-IRB CPN 026/ 15-16). Permission was sought from the management of the data collection outlets and informed consent (written) were obtained from the participants.

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Beyond the diagnosis: a qualitative exploration of the experiences of persons with hepatitis B in the Accra Metropolis, Ghana

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Beyond the diagnosis: a qualitative exploration of the experiences of persons with hepatitis B in the Accra Metropolis, Ghana

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ABSTRACT

Objective: This study explored the experiences of people with hepatitis B in the Accra metropolis.

Design: The study employed qualitative exploratory descriptive design with purposive sampling technique. Data were collected through face-to-face interview and transcribed verbatim. The data were analysed using content analysis.

Settings: Participants were recruited from one government and one mission hospital in Ghana.

Participants: Fourteen (14) individuals aged between 26 and 45 years with hepatitis B infection were interviewed.

Results: The findings of the study showed that people with Hepatitis B in the Accra metropolis lacked awareness about the infection. Furthermore, they experienced psychological and social problems especially when they were initially informed about their hepatitis B status. Sadness, fear, shock, shame, and disbelief were some of the experiences reported by participants. Coping strategies adopted include religiosity, diversional coping strategy and lifestyle modification.

Conclusions: It is, therefore, necessary as a country to integrate hepatitis B counselling into the already existing HIV structures in the health delivery system to offer support for individuals diagnosed with hepatitis B. Furthermore, it is important to draw lessons from the process used in the diagnosis of HIV particularly, in ensuring that people provide consent for being tested.

Key Words: Experience, Ghana, Hepatitis B, Infection

Strengths and limitations of this study

- This study is the first to explore the experiences of individuals with hepatitis B in Ghana and Africa. However, the qualitative design makes the finding not generalizable to the entire people with hepatitis B in Ghana.
- The study is limited by the recruitment of only people within the age bracket of 26 to 45 years and few men participating in the study.
- Furthermore, the participants had lived with their diagnosis between one to five years.

INTRODUCTION

Hepatitis B viral (HBV) infection remains one of the most important public health concerns worldwide. About 248 million people are documented positive of hepatitis B globally.¹ In 2010, HBV infection was found to be the tenth leading cause of global deaths and about 50% of deaths as a result of liver cancer were attributed to the infection.^{2,3} The consequences of HBV infection such as liver cirrhosis, hepatic failure and hepatocellular carcinoma are well documented to cause approximately 780,000 deaths annually on a global scale.^{2,4,5}

Even though no global estimate of economic impact of HBV infection was found, it is well documented that hepatitis B imposes an enormous economic burden on patients, families, health system and the society at large spanning from health care cost, cost of treatment and work loss.^{6,7,8} For instance, a study done in Vietnam showed that the total cost of treatment of hepatitis B and its complication was estimated to be US \$ 4.4 million nationally and the patient suffers a huge cost of care when the condition becomes more severe.⁸

Currently, HBV infection is receiving international recognition and attention from the World Health Organisation (WHO) and the World Health Assembly with recent emphasis on four axes: raising awareness, promoting partnership and mobilising resources; developing evidenced-based policy and data for action; prevention of transmission; and increasing access to screening, care, and treatment.⁹ This attention is demonstrated by the development of the first WHO guideline for prevention, care and treatment of persons living with HBV infection.¹⁰ More so, the health target for the sustainable development goal three which seeks to combat hepatitis by 2030^{11,12} add onto the global priority on viral hepatitis.

Ghana is endemic with hepatitis B with about 8% to 20% of the adult population estimated to be living with the infection.^{13,14} The long-term consequences of the infection are also reported to account for 42.9% (n=70) of liver cirrhosis in the country.¹⁵ As part of Ghana's response to hepatitis B prevention and control, hepatitis B vaccine was added to the Expanded Programme on Immunisation (EPI) in January 2002.¹⁶ This new vaccine was combined with DPT, and Haemophilus influenza type b (Hib) commonly referred to as pentavalent vaccine.¹⁶ The vaccine is administered to children at 6, 10 and 14 weeks after birth. Generally, hepatitis B testing and vaccination are offered for a fee in most health facilities because it is not covered by the Ghana National Health Insurance Scheme. In recent times, some hospitals have implemented mandatory screening of pregnant women as part of antenatal care services but not universal nationwide.¹⁷ Additionally, only a few hospitals provide specialised liver clinic for people with hepatitis B in Ghana.

Global evidence indicates that living with HBV infection is associated with social and psychological afflictions such as stigma, discrimination, anxiety, depression and low quality of life.^{18 19 20 21 22 23 24 25} However, in spite of the high prevalence (i.e. 8-20%) of hepatitis B in Ghana, no study was identified by the researchers that sought to explore the experiences of persons with HBV infection. This study, therefore aimed at documenting the experiences of people with HBV infection and their coping strategies in the Accra Metropolis to inform policy and programme designs.

METHODS

Study design

Qualitative exploratory descriptive design was used. This design was appropriate because according to Grove, Burn and Grays,²⁶ an individual experience is unique to him/her and can be in the best position to give an account and meanings to their own experiences. Furthermore, a qualitative investigation was imperative given the lack of previous research investigating the lived experience of people with hepatitis B in Africa generally and Ghana specifically, and the need to ensure that the perspective of people with hepatitis B could be properly investigated.

Study Setting

The study was conducted in the Greater Accra region. It is the smallest among the ten administrative regions in Ghana. It occupies a total land area of 3245 square kilometres.²⁷ Greater Accra region is found in the South-Central part of Ghana and shares boundaries with the Eastern region to the North, Central region to the West, Volta region to the East and the Gulf of Guinea to the South.²⁷ According to the 2010 population and housing census, about 4,010,050 people reside in the region.²⁷ One mission hospital and one government hospital in the Accra metropolis were used as data collection sites. These hospitals were selected because they are district hospitals that offer hepatitis B screening, vaccination and support.

Participant's eligibility

Inclusion Criteria

Participants were included in the study if they were 18 years and above and had tested hepatitis B (HBsAg) positive for six (6) months or more and consented to participate.

Exclusion Criteria

People living with hepatitis B who were not medically stable were excluded from the study. These are individuals who were terminally ill and had less energy to go through the interview session.

Sampling Method and Sample Size

Purposive sampling technique was employed to select people with hepatitis B who met the inclusion criteria. A purposive sampling technique is a non-probability sampling method in which a researcher selects participants based on the inclusion criteria and purpose of the study. In this case, the researchers were interested in informants who were willing to give information by their experience.²⁸ This was however appropriate for this study because it assisted the researchers to gain an insight into a new area and understood complex experiences.²⁶ Fourteen (14) out of the eighteen (18) participants contacted agreed to participate in the study. Those who refused to take part cited time constraint as reason. Data were saturated at the eleven (11) participants'. Data saturation is the point at which no new

information is obtained during an interview.²⁹ Data collection continued despite saturation to determine new emerging issues.

Data Collection Tool

Face-to-face in-depth interview was conducted. This was achieved by using semi-structured interview guide to collect data from each participant. The guide had both open and close-ended questions which allowed the researchers to probe until in-depth information was obtained from each participant. The guide was designed based on the study objectives and literature and it is included as supplementary file 1. Questions focused on feeling after diagnosis; perception of life after testing hepatitis B positive; effect of a positive result and coping strategies adopted. Additionally, field note was taken during the interview session.

Data Collection Procedure

Participants' recruitment commenced after ethical clearance was obtained from the Institutional Review Board of Noguchi Memorial Institute for Medical Research of the University of Ghana. Also, permission from the management of the data collection sites was obtained. Individuals diagnosed with hepatitis B were identified through the hospitals register with the assistance of the health care providers. Potential participants were contacted through telephone calls. The purpose of the study was explained in detail to those who were contacted. A convenient time and venue for each participant were arranged after they had consented to participate in the study. Those agreed to take part in the study were given an informed consent form to sign. Furthermore, consent of each participant was sought to record the interview session using audiotape recorder after its rationale of record keeping for reference purpose has been explained to them. Data were collected between January and February 2016 mostly in the homes of the participants. Each interview lasted between 45 and 60 minutes. Data collection was halted when participants expressed a feeling of apprehension when recounting their experiences and counselling was offered to those who were emotionally disturbed during the interview. The interviews were conducted by the principal investigator (CAA).

Data Analysis

Data were analysed using content analysis technique. The researchers played and listened to the audiotaped interviews and transcribed verbatim to familiarise themselves with the data. The three researchers coded the data individually, followed by series of group discussions of the codes and the generation of the major themes. The researchers however ensured that there were linkages between the themes and the codes. Sub-themes were created from the themes and the study findings are presented using the themes and the sub-themes.

Methodological Rigour (Trustworthiness)

Trustworthiness can be achieved by establishing credibility, transferability, dependability and confirmability.³⁰ This current study took into consideration all the rigour above. Credibility was achieved by piloting the interview guide using two participants from a district hospital in Accra. Member checking was done concurrently with data collection. Additionally, all data collected including recorded voices, transcription, field diaries were compiled into an audit trail. Transferability was ensured through a detailed description of the context in which the study was carried out. The research setting, sample and sampling technique and data collected from participants are reported in detail. More so, rich and accurate quotations of participant's response were quoted verbatim in this study. To ensure dependability, all field notes, transcription and voice recorded are kept in an audit trail. Furthermore, the researchers ensured confirmability by keeping an audit trail.

RESULTS

Demographic Characteristics

The study recruited a total of fourteen (14) persons with hepatitis B. Participants were within the age range of 26 years to 45 years and they were all Ghanaians. Seven of the participants had tertiary level education, five had a primary level education and two had no formal education. Two participants were single, three divorced after being tested hepatitis B positive and the remaining nine were still married. Females were eleven with only three males. The participants have been living with the infection for one to five years. None of the participants were on regular monitoring and prescribed treatment. Participants were diagnosed either at the time of pregnancy as part of their ANC routine laboratory investigations or through outreach services in churches or school programmes. Pseudonyms were used to ensure anonymity of participants.

Individual Level Factors

This theme describes the individual level factors that influence one’s social and psychological experiences. The study revealed that persons living with hepatitis B suffer various degree of psychological challenges including sadness, worries, fear, shock, shame, and disbelief. Furthermore, lack of awareness of the disease and blame was noted among some study participants.

Lack of Awareness

The findings showed that 9 out of 14 participants were not aware of HBV infection before they were diagnosed positive. Moreover, those who were aware had some knowledge gap about the infection. Some participants admitted their ignorance, but others classified the population in general to be deficient of hepatitis B related information as compare to HIV which is known by many.

“As for hepatitis B, I didn’t know about it until I got infected. What I knew to be deadly is HIV. It was the laboratory man who educated me about the disease that it is also dangerous”
[Sozo]

“As for HIV we all know about it but this hepatitis B, it is new to us. I only heard about it on radio, but I didn’t know what it was” [Momo]

Sadness/ Worries /Fear

Most participants reported that they were sad, worried and scared about their HBV positivity. According to them, this psychological trauma was more visible few days after diagnosis. More so, participants who were aware of hepatitis B infection and its associated complications manifested more of these symptoms.

“Because I have heard about the seriousness of the disease on a radio, I felt so scared and worried. In fact, I started sweating and suddenly became weak in my bones. Fear gripped me so badly that my whole day was spoilt. I was scared until I went on the internet to read about it then I realised it is not as dangerous as HIV as said on the radio. It was after knowing that I became a bit relaxed” [Kim]

Participants who knew someone who had died of the disease were very much terrified when they got to know their status.

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3 *"My friend was told that she had hepatitis B about five years ago. She then started falling ill*
4 *more often and finally died last year. So when I was told I was hepatitis B positive, I was*
5 *scared by the result"* [Maju]
6

7
8 The primary driver of the psychological affliction associated with the infection is the
9 comparison of hepatitis B with the disease Human Immuno-deficiency. Most participants
10 perceived hepatitis B to be more dangerous than HIV and therefore felt their life will soon
11 come to an end. Additionally, the absence of informed consent before testing and inaccurate
12 information given to people who are diagnosed with hepatitis B also contributed to their
13 negative experiences.
14

15 *"I think the sadness is a normal feeling because we hear the disease is more dangerous than*
16 *HIV so it means that you have a short life. You can die at any time. That makes me sad. I*
17 *think about my children. What will happen to them if I die and leave them behind? These are*
18 *the things I think about"* [Hani]
19

20
21 *"You know, some people say on the radio that hepatitis B is more serious than HIV and I*
22 *know how people with HIV end up to become. So I was imagining myself being in the worst*
23 *situation than someone with HIV.Also, the liver is only one, so if it gets spoilt then that*
24 *means my life will finish"* [Kim]
25

26 Some participants reported that hepatitis B adverts on radio and television, particularly those
27 presented by herbal medicine practitioners, did fuel their fear. Undoubtedly, most of the
28 airwaves in Ghana allow herbal practitioners to sell their products on radio and television and
29 therefore it is common to hear myth about hepatitis B being discussed. A participant
30 recounted her experience.
31

32 *"I only think about it (hepatitis B) when I see an advert on television.... Because the way they*
33 *describe it as very dangerous, I become so scared, especially the herbal medicine sellers.*
34 *They sound so scary as if you will die tomorrow when infected. At that moment, I get so*
35 *afraid that as soon as it is over, then I become okay."* [Maju]
36
37
38

39 Shock /Shame/ Disbelief

40
41 The study found that six of the participants were shocked when they were informed of their
42 positive results. This according to them occurred because they were not prepared at the time
43 of diagnosis to receive a positive test result. Some participants revealed that they got tested
44 for hepatitis B because per the policy of the hospital they attended for delivery, it was
45 compulsory for every pregnant woman to have hepatitis B screening before delivery.
46

47 *"Well...I felt very bad and was thinking otherwise like how come I have this virus".*
48 *"I was really shocked!"* [Yoland]
49

50
51 According to Hani, knowing that she was hepatitis B positive was the greatest surprise in her
52 life. She indicated that her sense of dignity was lost when she got to know her positive status.
53 She lamented:
54

55 *"Hmmm! I could not believe it. I was more than confident before the testing that I will be*
56 *negative. Growing up as a young lady, I never involved in any bad practices such as sleeping*
57
58
59
60

with men. I remained a virgin till I married my husband, so I have never thought of being positive. I felt ashamed and shocked!" [Hani]

The effects of participants' bitter experiences were noted to affect their job since mental distortion were reported. This was much pronounced in a situation whereby participants were not able to vividly establish the cause of their infection.

"Sometimes, I lose concentration even at work, especially when I remember that I am hepatitis B positive. I sometimes think to see if I can pinpoint the main means that I got the disease. That alone put me into psychological stress" [Hani]

Blame

The majority of the female participants did not hesitate to link their source of infection to their spouse's. According to most of them, their spouses indulge in extra marital affairs and therefore might have gotten themselves infected through their multi-sexual behaviours. Some even inquired from the health care providers to ascertain such possibilities. Maju narrated:

"I first asked the nurses if my husband might be the one who has given me the infection but I was told not necessarily because there are so many ways I can get it" [Maju]

Furthermore, participants who perceived their partners to be unfaithful in their marriage confidently attributed their source of infection to them. This is well said in the two quotes by Yolanda and Maju below:

".....I was putting the blame on my husband. I suspected him because when I was with him, he was always flirting with other ladies" [Yolanda]

"I have seen him (husband) many times with other women, so I will not be surprised if he is the one who has given me this dangerous disease. He does not live a clean life. What I mean is that he likes chasing girls" [Maju]

On the other hand, some of the participants resorted to blaming as a strategy to let their spouses go for hepatitis B test. This was more common among women who suspected their partners to be promiscuous. Even though hepatitis B is transmitted predominantly through mother-to-child in the study setting, many believe that it is sexually transmittable like HIV. This explains the reactions of some participants toward their spouses.

"I said....You (spouse) need to go for check-up so that we know where it is coming from... whether from you or not?"[Yolanda]

"I only wanted to be sure if my husband is not the one who has given me the disease and therefore I told him to go for the test so that we all understand why?" [Hani]

Sozo reported how she finds it difficult to forgive her mother after she got to know of her positive status. According to her, she could have prevented herself from being positive when she tested negative during hepatitis B screening at school. But because her parent failed to recognise the significance of hepatitis B vaccination and therefore refused to pay for it, she is now positive five years down the line. She lamented:

1
2
3 *"Hmmm! My story is different. I could have prevented myself from this disease. About five*
4 *years ago I had the test and it was negative. By then I was in school, so I called my mum to*
5 *inform her about the cost of vaccination, but she said no. That is why I feel that she is the*
6 *cause of my infection"* [Sozo]
7

8 **Coping strategies**

9
10 Some of the participants were affected by the diagnosis and therefore resorted to different
11 approaches to cope with it. Others had superstitious belief that they are bewitched by
12 someone and that explains why they are HBV positive. Revelations by some spiritual leaders
13 made others accept the contribution of spirituality to the cause of the disease.
14 Notwithstanding, some participants recognised the disease as a normal occurrence.
15

16 **Religiosity**

17 Religion plays a major role in the life of many Ghanaians. They are always quick to attribute
18 the causes of diseases to an evil spirit. For many Ghanaians, God is the determinant of a
19 person's destiny and therefore whatever comes their way are the plans of God concerning
20 their life. This assertion by most of the participants made them believe God for healing and
21 therefore prayed with the hope that they will be healed one day.
22

23
24 *"The day I was informed that I have this disease, all what I said was my enemies had raised*
25 *a war against me. I went on my knees and prayed that the Lord should deal with them*
26 *because He is the only one who can fight my battle for me"* [Kuku]
27

28
29 *"As for me, I only depend on God for my healing. Sometimes, I go for a Bible and start*
30 *reading. I do that because I believe God has the power to heal all diseases"* [Maju]
31

32 Some participants depended on words of encouragement from their spiritual leaders to cope
33 with the disease. Yoland shares how her engagement with her pastor calmed her down.
34

35 *"It didn't affect me because we were having our pastor, so we informed him. He prayed*
36 *about it, and he said the second test shouldn't be positive. I didn't talk about it again and*
37 *didn't want to put it in my mind that I have this hepatitis B"* [Yoland]
38

39 **Diversion Approach**

40 Different people have various ways of dealing with chronic conditions. The study revealed
41 that majority of participants take off their minds from the disease as a means of coping with
42 it. This was noted as a strategy for many to overcome the stresses associated with the
43 condition.
44

45
46 *"I take it as normal. I don't think about it. I move my life freely. I did not put it in my mind,*
47 *so it doesn't move me to sit down and think about it"* [Momo]
48

49
50 *"I just brushed it off and not to think about it that I have hepatitis B. The more you put it in*
51 *your mind, the more you can't even move on in life"* [Yoland]
52

53 Maju also indicated that she avoids listening or watching programmes about hepatitis B
54 because it causes her to think about the disease.
55

56 *"When the advert comes, I take my mind off it"* [Maju]
57
58
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60

Lifestyle modification

Some participants changed their lifestyle after the diagnosis. This according to them was an attempt to prevent developing serious complications. Intake of alcohol and fatty foods were avoided by many.

“Before I got to know I was hepatitis B, I was drinking a lot of alcohol; I mean hard ones like “Akpateshie” (local gin). After knowing, I stopped because the nurse said what can kill me is the alcohol since it helps to destroy the liver fast. This made me to be afraid, and I ceased to drinking the alcohol. I now feel ok because I know that I will live a longer life” [Sozo]

Kora also shared how she has modified her lifestyle after receiving education on hepatitis B from a resourced person. She now strictly adheres to foods that are recommended for persons with hepatitis B infection. She had this to say:

“Luckily for me, where I attend church, the pastor’s wife has a little background of medicine so she always talks about hepatitis B. She has been teaching us how to live if you have it, the food you have to eat and that kind of stuff. So that is what I depend on” [Kora]

Furthermore, the study found that some lifestyle changes were a bit of worry to some of the participants. They perceived it as a burden because they have to live with the condition for the rest of their lives.

“Sometimes when you go out with friends, there are things you cannot do. You cannot take alcohol, there are foods you don’t have to eat then is like restricting yourself from so many things.” [Sozo]

DISCUSSION

In this study, people with hepatitis B demonstrated a limited level of awareness about the infection with some knowledge deficit before diagnosis. Similar findings are reported in several studies in other countries.^{31 32 33 34 35} For example, Dahl et al.³¹ found that 50% (N=55) of people with hepatitis B mentioned kissing and mosquito bites as sources of HBV mode of transmission. Interestingly, most participants in this present study were more familiar with HIV infection than HBV as shown by their frequent reference to HIV as a more dangerous and well-known disease than HBV. Perhaps, the high campaign programmes carried out over the years about HIV might be the reason underlying this revelation. However, this is not surprising since the recent Ghana Demographic and Health Survey report indicates 96% HIV awareness level among the population.³⁶ On the other hand, many of the participants in this study became aware of hepatitis B after their diagnosis. This is consistent with a study finding by Rafique et al.³⁷ in Pakistan. The low HBV awareness and knowledge level of the participants may also be due to fewer HBV programmes and outreach campaigns in most communities in Ghana as reported by Nkandawire et al.³⁸ in the Northern part of the country. This, therefore, suggests a huge hepatitis B response gap particularly in improving the awareness and knowledge of the disease in the general population including those living with the infection.

Furthermore, health professionals are documented to be the primary source of hepatitis B information to their clients³⁹ but surprisingly, many study findings have shown inadequacy on their knowledge regarding HBV infection.^{17 40} A particular example is a study finding by Chao et al.⁴⁰ which revealed that about 34% of health professionals failed to recognise that

chronic HBV infection is usually asymptomatic and also failed to identify all the modes of HBV transmission. Many factors account for this gap in knowledge among this critical staff. One of these factors may be the lack of training of health care providers on current information on hepatitis B. This is supported by a study by Adjei et al.¹⁷ in the Eastern region of Ghana whereby 49.2% of physicians and midwives in the study area had never attended workshop on hepatitis B after their formal training. This may have negative implications on their practice including management, care and support of people with hepatitis B.

Consistent with other studies in Asia, Malaysia and Australia,^{24 25 37 39} the current study found that most participants were sad, worried and entertained some fears when they got to know their hepatitis B positive status. This was partly because participants were not very much prepared for positive HBV outcome before the diagnosis. It is worth mentioning that there are no clear guidelines on the management of HBV infection in many health facilities in Ghana and therefore information about what to do next after positive hepatitis B result is not well communicated to clients including follow-up care. This among other things leaves the infected person in a state of confusion after diagnosis. Perhaps, the non-existence of informed consent before hepatitis B testing and inaccurate information given after diagnosis may explain why some participants experienced psychological distress. There is the need to learn from the experience of the processes used in the diagnosis of HIV for hepatitis B, particularly in ensuring that people provide consent for being tested, and that information about the infection and referral information is provided to people upon diagnosis.

Furthermore, it was found that majority of the participants interviewed expressed fear and worry about their HBV positivity and this was more pronounced among those who were very much aware of the complications associated with the infection such as liver cancer, and cirrhosis. In support of this finding, a study done in Malaysia documented that positive HBV-infected persons with some knowledge on the consequences of their positive results expressed more fears as compared to those with inadequate knowledge.²⁵ This psychological distress happens because people with hepatitis B consider themselves as possible sources of infection to their family and friends.^{24 31}

Hepatitis B infected persons experienced shock, disbelief and shame of their positive status particularly when they were first informed about their positive result. This corroborates with other related study findings.^{25 35} However, the reaction of the current study participants could be because the testing was not voluntary for many but rather as part of the health facility protocol and therefore participants had no choice but to comply. Even though the intention to avert mother to child transmission is good, it is equally important also to consider the psychosocial burden that those who test positive experience for appropriate intervention in that regard. Moreover, because people who are HBV positive are unable to point out the source of their infection,^{32 37} it can, therefore, be speculated to be one of the reasons which account for the shock and disbelief that characterises the disease diagnosis. The result of this experience has the tendency of exposing people with hepatitis B to depression and anxiety.¹⁸

This study had strengths and limitations. It is the first to explore the experiences of individuals with hepatitis B in Ghana and Africa. However, the qualitative design employed makes the finding not generalizable to the entire people living with HBV in Ghana. The study is limited by the recruitment of only people within the age bracket of 26 to 45 years and few men participating in the study. Furthermore, the participants had lived with their diagnosis between one to five years.

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Conclusion

The outcome of the study showed psychological and social challenges that HBV-infected persons experienced right from the time of diagnosis throughout their life. It therefore, suggests a more public health intervention that can critically respond appropriately to this burden currently confronting people with hepatitis B in Ghana. We therefore, recommend integration of hepatitis B counselling (pre-test and post-test counselling) in the already existing HIV structures. Furthermore, it is also important as a country to draw lessons from the process used in the diagnosis of HIV particularly, in ensuring that people provide consent for being tested.

Abbreviation

HBV- Hepatitis B Virus; WHO-World Health Organisation

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Availability of data and materials

Transcribed data cannot be shared since participants did not consent to this. However, they are with the authors to avoid possible identification of the quotations with any of the participants.

Authors Contributions

CAA conceptualised the study. CAA, FN, ESD designed the study and the interview guide. Data were collected by CAA. Data analysis was done by FN, ESD and CAA. Manuscript was critically reviewed by FN and ESD. All authors read and approved the final manuscript.

Competing Interest

The authors declare no competing interest

Consent for publication

Not applicable

Ethical Approval

Ethical clearance was obtained from Institutional Review Board of Noguchi Memorial Institute for Medical Research (Approval number NMIMR-IRB CPN 026/ 15-16). Permission was sought from the management of the data collection sites, and informed consent (written) was obtained from the participants.

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Supplementary file 1: Interview Guide

1. Please tell me about yourself
 - a. Age?
 - b. Sex?
 - c. Occupation?
 - d. Tribe?
 - e. Education?
 - f. Your marital status?
 - g. How many children do you have?
 - h. When were you first diagnosed hepatitis B positive?
 - i. How were you diagnosed?
2. Can you share with me how you felt when you were first informed that you were positive for hepatitis B? (Probe).
3. Ever since you got to know your hepatitis status, how do you perceive life in general? (Probe). Describe
4. Can you share with me if your positive status has any psychological effect on your personal life? (Probe). Give example
5. With all the issues you have discussed with me, can you share with me some strategies you have put in place in coping with the infection? (Probe). Give example

COREQ (CONsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the inter view or focus group?	
Duration	21	What was the duration of the inter views or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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BMJ Open

Beyond the diagnosis: a qualitative exploration of the experiences of persons with hepatitis B in the Accra Metropolis, Ghana

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Beyond the diagnosis: a qualitative exploration of the experiences of persons with hepatitis B in the Accra Metropolis, Ghana

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ABSTRACT

Objective: This study explored the experiences of people with hepatitis B in the Accra metropolis.

Design: The study employed qualitative exploratory descriptive design with purposive sampling technique. Data were collected through face-to-face interview and transcribed verbatim. The data were analysed using content analysis.

Settings: Participants were recruited from one government and one mission hospital in Ghana.

Participants: Fourteen (14) individuals aged between 26 and 45 years with hepatitis B infection were interviewed.

Results: The findings of the study showed that people with hepatitis B in the Accra metropolis were unclear about the impact of their infection. Furthermore, they experienced psychological and social problems especially when they were initially informed about their hepatitis B status. Sadness, fear, shock, shame, and disbelief were some of the experiences reported by participants. Coping strategies adopted include religiosity, denial and lifestyle modification.

Conclusions: It is therefore necessary as a country to integrate hepatitis B counselling into the already existing HIV structures in the health delivery system to offer support for individuals diagnosed with hepatitis B. Furthermore, it is important to draw lessons from the process used in the diagnosis of HIV particularly in ensuring that people provide consent for being tested.

Key Words: Experience, Ghana, hepatitis B, Infection

Strengths and limitations of this study

- This study is the first to explore the experiences of people with hepatitis B in Ghana and Africa.
- However, the small sample size makes the finding not generalizable to the entire people with hepatitis B in Ghana.
- Additionally, the outcome of this study will assist in developing population-based surveys to quantify the extent of knowledge of people with hepatitis B in order to develop appropriate public health interventions in Ghana.
- The study is limited by the recruitment of only people within the age bracket of 26 to 45 years and few men participating in the study.
- The participants have lived with their diagnosis between one to five years.

INTRODUCTION

Hepatitis B viral (HBV) infection remains one of the most important public health concerns worldwide. About 248 million people are documented positive of hepatitis B globally.¹ In 2010, hepatitis B was found to be the tenth leading cause of global deaths and about 50% of deaths as a result of liver cancer were attributed to the infection.^{2 3} The consequences of the infection such as liver cirrhosis, hepatic failure and hepatocellular carcinoma are well documented to cause approximately 780,000 deaths annually on a global scale.^{2 4 5}

Even though no global estimate of economic impact of hepatitis B was found, it is well documented that hepatitis B imposes an enormous economic burden on patients, families, health system and the society at large spanning from health care cost, cost of treatment and work loss.^{6 7 8} For instance, a study done in Vietnam showed that the total cost of treatment of hepatitis B and its complication was estimated to be US \$ 4.4 million nationally and the patient suffers a huge cost of care when the condition becomes more severe.⁸

Currently, hepatitis B is receiving international recognition and attention from the World Health Organisation (WHO) and the World Health Assembly with recent emphasis on four axes: raising awareness, promoting partnership and mobilising resources; developing evidenced-based policy and data for action; prevention of transmission; and increasing access to screening, care, and treatment.⁹ This attention is demonstrated by the development of the first WHO guideline for prevention, care and treatment of persons with hepatitis B.¹⁰ More so, the health target for the sustainable development goal three which seeks to combat hepatitis by 2030^{11 12} add onto the global priority on viral hepatitis.

Ghana is endemic with hepatitis B with about 8% to 20% of the adult population estimated to be living with the infection.^{13 14} The long-term consequences of the infection are also reported to account for 42.9% (n=70) of liver cirrhosis in the country.¹⁵ As part of Ghana's response to hepatitis B prevention and control, hepatitis B vaccine was added to the Expanded Programme on Immunisation (EPI) in January 2002.¹⁶ This new vaccine was combined with DPT, and Haemophilus influenza type b (Hib) commonly referred to as pentavalent vaccine.¹⁶ The vaccine is administered to children at 6, 10 and 14 weeks after birth. Generally, hepatitis B testing and vaccination are offered for a fee in most health facilities in Ghana because it is not covered by the National Health Insurance Scheme. In recent times, some hospitals have implemented mandatory screening of pregnant women as part of

antenatal care services but not universal nationwide.¹⁷ Only a few hospitals provide specialised liver clinic for people with hepatitis B in Ghana.

Global evidence indicates that living with hepatitis B is associated with social and psychological afflictions such as stigma, discrimination, anxiety, depression and low quality of life.¹⁸⁻²⁵ However, in spite of the high prevalence (i.e. 8-20%) of hepatitis B in Ghana, no study was identified by the researchers that have documented the experiences of persons with hepatitis B. This study therefore sought to understand the psychological and social impact of hepatitis B on those diagnosed with the infection including their coping strategies in the Accra Metropolis to inform policy and programme design.

METHODS

Study design

Qualitative exploratory descriptive design was used. This design was appropriate because according to Grove, Burn and Grays,²⁶ an individual experience is unique to him/her and can be in the best position to give an account and meanings to their own experiences. Furthermore, a qualitative investigation was imperative given the lack of previous research investigating the lived experience of people with hepatitis B in Africa generally and Ghana specifically, and the need to ensure that the perspective of people with hepatitis B could be properly investigated.

Study Setting

The study was conducted in the Greater Accra region. It is the smallest among the ten administrative regions in Ghana. It occupies a total land area of 3245 square kilometres.²⁷ Greater Accra region is found in the South-Central part of Ghana and shares boundaries with the Eastern region to the North, Central region to the West, Volta region to the East and the Gulf of Guinea to the South.²⁷ According to the 2010 population and housing census, about 4,010,050 people reside in the region.²⁷ One mission hospital and one government hospital in the Accra metropolis were used as data collection sites. These hospitals were selected because they are district hospitals that offer hepatitis B screening, vaccination and support.

Participant's eligibility

Inclusion Criteria

Participants were included in the study if they were 18 years and above and had tested hepatitis B (HBsAg) positive for six (6) months or more and consented to participate.

Exclusion Criteria

People living with hepatitis B who were not medically stable were excluded from the study. These are individuals who were terminally ill and had less energy to go through the interview session.

Sampling Method and Sample Size

Purposive sampling technique was employed to select people with hepatitis B who met the inclusion criteria. A purposive sampling technique is a non-probability sampling method in which a researcher selects participants based on the inclusion criteria and purpose of the study. In this case, the researchers were interested in informants who were willing to give information about their experience.²⁸ This was however appropriate for the study because it assisted the researchers to gain an insight into a new area and understood complex experiences.²⁶ Fourteen (14) out of the eighteen (18) participants contacted agreed to

participate in the study. Those who refused to take part cited time constraint as reason. Data were saturated at the eleven (11) participants. Data saturation is the point at which no new information is obtained during an interview.²⁹ Data collection continued despite saturation to determine new emerging issues.

Data Collection Tool

Face-to-face in-depth interview was conducted. This was achieved by using semi-structured interview guide to collect data from each participant. The guide had both open and close-ended questions which allowed the researchers to probe until in-depth information was obtained from each participant. The guide was designed based on the study objectives and literature and it is included as supplementary file 1. Questions focused on feeling after diagnosis; perception of life after testing hepatitis B positive; effect of a positive result and coping strategies adopted. Additionally, field note was taken during the interview session.

Data Collection Procedure

Participants' recruitment commenced after ethical clearance was obtained from the Institutional Review Board of Noguchi Memorial Institute for Medical Research of the University of Ghana. Also, permission from the management of the data collection sites was obtained. Individuals diagnosed with hepatitis B were identified through the hospitals register with the assistance of health care providers. Potential participants were contacted through telephone calls. The purpose of the study was explained in detail to those who were contacted. A convenient time and venue for each participant was arranged after they had consented to participate in the study. Those agreed to take part in the study were given an informed consent form to sign. Furthermore, consent of each participant was sought to record the interview session using audiotape recorder after its rationale of record keeping for reference purpose has been explained to them. Data were collected between January and February 2016 mostly in the homes of the participants. Each interview lasted between 45 and 60 minutes. One participant was emotionally disturbed (tears were flowing down her cheek) when recounting her experiences. Interview was halted and counselling was provided until the participant became emotionally stable and consented to continue. The interviews were conducted by the principal investigator (CAA).

Data Analysis

Data were analysed using content analysis technique. The researchers played and listened to the audiotaped interviews and transcribed verbatim to familiarise themselves with the data. The three researchers coded the data individually, followed by series of group discussions of the codes and the generation of the major themes. The researchers however ensured that there were linkages between the themes and the codes. Sub-themes were created from the themes and the study findings are presented using the themes and the sub-themes.

RESULTS

Demographic Characteristics

The study recruited a total of fourteen (14) persons with hepatitis B. Participants were within the age range of 26 years to 45 years and they were all Ghanaians. Seven of the participants had tertiary level education, five had a primary level education and two had no formal education. Two participants were single, three divorced after being tested hepatitis B positive and the remaining nine were still married. Females were eleven with only three males. The participants have been living with the infection for one to five years. None of the participants were on regular monitoring or prescribed treatment. Participants were diagnosed either at the time of pregnancy as part of their antenatal care routine laboratory investigations or through

outreach services in churches or school programmes. Pseudonyms are used to ensure anonymity of participants.

Individual Level Factors

This theme describes the individual level factors that influence one’s social and psychological experiences. The study revealed that persons living with hepatitis B suffer various degrees of psychological challenges including sadness, worries, fear, shock, shame, and disbelief. Furthermore, lack of awareness of the disease and blame was noted among some study participants.

Lack of Awareness

The findings showed that 9 out of 14 participants were not aware of hepatitis B before they were diagnosed positive. Moreover, those who were aware had some knowledge gap on the impact of their infection. Some participants admitted their ignorance, but others classified the population in general to be deficient of hepatitis B related information as compare to HIV which is known by many.

“As for hepatitis B, I didn’t know about it until I got infected. What I knew to be deadly is HIV. It was the laboratory man who educated me about the disease that it is also dangerous”
[Sozo]

“As for HIV we all know about it but this hepatitis B, it is new to us. I only heard about it on radio, but I didn’t know what it was” [Momo]

Sadness/ Worries /Fear

Most participants reported that they were sad, worried and scared about their hepatitis B positivity. According to them, this psychological trauma was more visible a few days after diagnosis. More so, participants who were aware of hepatitis B and its associated complications manifested more of these symptoms.

“Because I have heard about the seriousness of the disease on a radio, I felt so scared and worried. In fact, I started sweating and suddenly became weak in my bones. Fear gripped me so badly that my whole day was spoilt. I was scared until I went on the internet to read about it then I realised it is not as dangerous as HIV as said on the radio. It was after knowing that I became a bit relaxed” [Kim]

Participants who knew someone who had died of the disease were very much terrified when they got to know their status.

“My friend was told that she has hepatitis B about five years ago. She then started falling ill more often and finally died last year. So when I was told I was hepatitis B positive, I was scared by the result” [Maju]

The primary driver of the psychological affliction associated with the infection is the comparison of hepatitis B with the disease Human Immuno-deficiency virus. Most participants perceived hepatitis B to be more dangerous than HIV and therefore felt their life will soon come to an end. Additionally, the absence of informed consent before testing and inaccurate information given to people who are diagnosed with the infection also contributed to their negative experiences.

“I think the sadness is a normal feeling because we hear the disease is more dangerous than

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3 *HIV so it means that you have a short life. You can die at any time. That makes me sad. I*
4 *think about my children. What will happen to them if I die and leave them behind? These are*
5 *the things I think about” [Hani]*
6

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8 *“You know, some people say on the radio that hepatitis B is more serious than HIV and I*
9 *know how people with HIV end up to become. So I was imagining myself being in the worst*
10 *situation than someone with HIV.....Also, the liver is only one, so if it gets spoilt then that*
11 *means my life will finish” [Kim]*
12

13 Some participants reported that hepatitis B adverts on radio and television particularly those
14 presented by herbal medicine practitioners did fuel their fear. Undoubtedly, most of the
15 airwaves in Ghana allow herbal practitioners to sell their products on radio and television and
16 therefore it is common to hear myth about hepatitis B being discussed. A participant
17 recounted her experience.
18

19 *“I only think about it (hepatitis B) when I see an advert on television.... Because the way they*
20 *describe it as very dangerous, I become so scared, especially the herbal medicine sellers.*
21 *They sound so scary as if you will die tomorrow when infected. At that moment, I get so*
22 *afraid that as soon as it is over then I become okay.” [Maju]*
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25 Shock /Shame/ Disbelief

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27 The study found that six of the participants were shocked when they were informed of their
28 positive results. This according to them occurred because they were not prepared at the time
29 of testing to receive a positive result. Some participants revealed that they got tested for
30 hepatitis B because per the policy of the hospital they attended for delivery, it was
31 compulsory for every pregnant woman to have hepatitis B screening done.
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33

34 *“Well...I felt very bad and was thinking otherwise like how come I have this virus. I was*
35 *really shocked!” [Yoland]*
36

37 According to Hani, knowing that she was hepatitis B positive was the greatest surprise in her
38 life. She felt that her sense of dignity was lost after she got to know her positive status. She
39 lamented:
40

41 *“Hmmm! I could not believe it. I was more than confident before the testing that I will be*
42 *negative. Growing up as a young lady, I never involved in any bad practices such as sleeping*
43 *with men. I remained a virgin till I married my husband, so I have never thought of being*
44 *positive. I felt ashamed and shocked!” [Hani]*
45
46

47 The effects of participants' bitter experiences were noted to affect their job since mental
48 distortions were reported. This was much pronounced in a situation whereby participants
49 were not able to vividly establish the cause of their infection.
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51

52 *“Sometimes I lose concentration even at work especially when I remember that I am hepatitis*
53 *B positive. I sometimes think to see if I can pinpoint the main means that I got the disease.*
54 *That alone put me into psychological stress” [Hani]*
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57 Blame

The majority of the female participants did not hesitate to link their source of infection to their spouse's. According to most of them, their spouses indulge in extra marital affairs and therefore might have gotten themselves infected through their multi-sexual behaviours. Some even inquired from the health care providers to ascertain such possibilities. Maju narrated:

"I first asked the nurses if my husband might be the one who has given me the infection but I was told not necessarily because there are so many ways I can get it" [Maju]

Furthermore, participants who perceived their partners to be unfaithful in their marriage confidently attributed their source of infection to them. This is well said in the two quotes by Yolanda and Maju below:

".....I was putting the blame on my husband. I suspected him because when I was with him, he was always flirting with other ladies" [Yolanda]

"I have seen him (husband) many times with other women, so I will not be surprised if he is the one who has given me this dangerous disease. He does not live a clean life. What I mean is that he likes chasing girls" [Maju]

On the other hand, some of the participants resorted to blaming as a strategy to let their spouses go for hepatitis B test. This was more common among women who suspected their partners to be promiscuous. Even though hepatitis B is transmitted predominantly through mother-to-child in the study setting, many believe that it is sexually transmittable like HIV. This explains the reactions of some participants toward their spouses.

"I said....You (spouse) need to go for check-up so that we know where it is coming from... whether from you or not?"[Yolanda]

"I only wanted to be sure if my husband is not the one who has given me the disease and therefore I told him to go for the test so that we all understand why?" [Hani]

Sozo reported how she finds it difficult to forgive her mother after she got to know of her positive status. According to her, she could have prevented herself from being positive when she tested negative during hepatitis B screening at school. Unfortunately because her parent failed to recognise the significance of hepatitis B vaccination and therefore refused to pay for it, she is now positive five years down the line. She lamented:

"Hmmm! My story is different. I could have prevented myself from this disease. About five years ago I had the test and it was negative. By then I was in school, so I called my mum to inform her about the cost of vaccination, but she said no. That is why I feel that she is the cause of my infection" [Sozo]

Coping strategies

Some of the participants were affected by the diagnosis and therefore resorted to different approaches to cope with it. Others had superstitious belief that they are bewitched by someone and that explains why they are hepatitis B positive. Revelations by some spiritual leaders made others accept the contribution of spirituality to the cause of the disease. Notwithstanding, some participants recognised the disease as a normal occurrence. Religiosity, denial and lifestyle modification are coping strategies used by the participants.

Religiosity

Religion plays a major role in the life of many Ghanaians. They are quick to attribute the causes of diseases to an evil spirit. For many Ghanaians, God is the determinant of a person's destiny and therefore whatever comes their way are the plans of God concerning their life. This assertion by most of the participants made them believe God for healing and therefore prayed with the hope that they will be healed one day.

"The day I was informed that I have this disease, all what I said was my enemies had raised a war against me. I went on my knees and prayed that the Lord should deal with them because He is the only one who can fight my battle for me" [Kuku]

"As for me, I only depend on God for my healing. Sometimes, I go for a Bible and start reading. I do that because I believe God has the power to heal all diseases" [Maju]

Some participants depended on words of encouragement from their spiritual leaders to cope with the disease. Yoland shares how her engagement with her pastor calmed her down.

"It didn't affect me because we were having our pastor, so we informed him. He prayed about it, and he said the second test shouldn't be positive. I didn't talk about it again and didn't want to put it in my mind that I have this hepatitis B" [Yoland]

Denial

Different people have various ways of dealing with chronic conditions. The study revealed that majority of the participants took off their minds from the disease as a means of coping with it. This was noted as a strategy for many to overcome the stresses associated with the condition.

"I take it as normal. I don't think about it. I move my life freely. I did not put it in my mind, so it doesn't move me to sit down and think about it" [Momo]

"I just brushed it off and not to think about it that I have hepatitis B. The more you put it in your mind, the more you can't even move on in life" [Yoland]

Maju also indicated that she avoids listening or watching programmes about hepatitis B because it causes her to think about the disease.

"When the advert comes, I take my mind off it" [Maju]

Lifestyle modification

Some participants changed their lifestyle after the diagnosis. This according to them was an attempt to prevent developing serious complications. Intake of alcohol and fatty foods were avoided by many.

"Before I got to know I was hepatitis B, I was drinking a lot of alcohol; I mean hard ones like 'Akpeteshie' (local gin). After knowing, I stopped because the nurse said what can kill me is the alcohol since it helps to destroy the liver fast. This made me to be afraid, and I stopped drinking the alcohol. I now feel ok because I know that I will live a longer life" [Sozo]

Kora also shared how she has modified her lifestyle after receiving education on hepatitis B from a health care provider. She now strictly adheres to foods that are recommended for persons with hepatitis B infection. She had this to say:

“Luckily for me, where I attend church, the pastor’s wife has a little background of medicine so she always talks about hepatitis B. She has been teaching us how to live if you have it, the food you have to eat and that is what I depend on” [Kora]

Furthermore, the study found that some lifestyle changes were a bit of worry to some of the participants. They perceived it as a burden because they have to live with the condition for the rest of their lives.

“Sometimes when you go out with friends, there are things you cannot do. You cannot take alcohol, there are foods you don’t have to eat then is like restricting yourself from so many things.” [Sozo]

DISCUSSION

This study provides insight into the experiences of people with hepatitis B following their diagnosis. The study found that some participants had knowledge deficit and limited awareness about the impact of hepatitis B before diagnosis. Generally, participants consent were not sought before testing and therefore the outcome of the screening presented various forms of psychological trauma to majority of them. The illness experience made participants to employ different coping strategies including religiosity, denial and lifestyle modification.

Several studies in other countries have documented knowledge deficit among people with hepatitis B.³⁰⁻³⁴ For example, Dahl et al.³⁰ found that 50% (N=55) of people with hepatitis B identified kissing and mosquito bites as sources of hepatitis B transmission. Unlike HIV which is known by approximately 96% of Ghanaians,³⁵ hepatitis B awareness appears to be low in Ghana. Most participants became aware of the infection after their diagnosis. Perhaps, the high campaign programmes carried out over the years on HIV might be the reason underlying this revelation in Ghana. It is therefore important to develop and implement a population-based hepatitis B awareness campaign to augment the effort of the few Non-governmental organisations working on hepatitis B project in the country.³⁶

Consistent with other studies in Asia, Malaysia and Australia,^{24 25 37 38} the current study found that most participants were sad, worried and entertained some fears when they got to know their hepatitis B positive status. This experience was more pronounced among those who were very much aware of the complications associated with the infection such as liver cancer, and cirrhosis. Similarly in Malaysia, people with hepatitis B who had knowledge on the consequences of their positive results expressed more fears as compared to those with inadequate knowledge.²⁵ This psychological distress occurs because some hepatitis B positive individuals consider themselves as possible sources of infection to their families and friends.^{24 30} Moreover, the assumption of hepatitis B being associated with HIV may be fuelling the fear. It is worth mentioning that there are no clear guidelines on the management of hepatitis B in many health facilities in Ghana and therefore information about what to do next after positive hepatitis B result is not well communicated to clients including follow-up care. This among other things leaves the infected person in a state of confusion after diagnosis. The non-existence of informed consent before hepatitis B testing may explain why some participants experienced psychological problem. There is the need to learn from the experience of the processes used in the diagnosis of HIV for hepatitis B, particularly in ensuring that people provide consent for being tested, and that information about the infection and referral information is provided to people upon diagnosis.

Furthermore, some participants experienced shock, disbelief and shame of their status particularly when they were first informed about their positive test result. This corroborates with other related study findings.^{25 34} The reactions of the participants could be explained by the fact that screening was not voluntary for many but rather part of the health facilities protocol which failed to take into consideration pre-testing and post-testing counselling. Moreover, the shock and disbelief experience by people with hepatitis B after diagnosis can be speculated to occur because most people with hepatitis B are unable to point out the sources of their infection.^{32 37}

The study further found three ways in which people with hepatitis B cope with their disease; religiosity, denial and lifestyle modification. Religiosity plays a significant role in coping with chronic diseases^{39 40} and this is relevant in the context of Ghana where many people hold strong religious belief. Some participants attributed the cause of the disease to the activities of evil spirit and therefore relied on God and their spiritual heads for support. This may have negative effect on the health care seeking of people with hepatitis B with such belief and possibly lead to delay in reporting to the clinic for monitoring, care and support. More so, denial of hepatitis B status and its effect were found in the study as shown by the minimum attention participants placed on the infection. Similar study by Ng et al.²⁵ found that people with hepatitis B adopted a positive mind-set as a way of coping with their infection. It is also documented in literature that people with hepatitis B modified their lifestyle after diagnosis^{24 41} and the most common lifestyle changes include alcohol and smoking cessation, dietary changes and exercise. According to Mohamed et al.²⁴ out of 150 patients who reported as consumers of alcohol prior to hepatitis B diagnosis, 87.3% reduced the intake or stopped after knowing their status. About 57% made healthier food choices and 46.6% increased their exercise activities²⁴. Even though there is no evidence supporting dietary prescriptions for people with hepatitis B, many people resort to diet low in fat as a way of ensuring a healthy life.

This study had strengths and limitations. It is the first to explore the experiences of individuals with hepatitis B in Ghana and Africa. However, the small sample size makes the finding not generalizable to the entire people with hepatitis B in Ghana. Additionally, the outcome of this study will assist in developing population-based surveys to quantify the extent of knowledge of people with hepatitis B in order to develop appropriate public health interventions in Ghana. The study is limited by the recruitment of only people within the age bracket of 26 to 45 years and few men participating in the study. Furthermore, the participants have lived with their diagnosis between one to five years.

Conclusion

The outcome of the study showed psychological and social challenges that persons with hepatitis B experienced right from the time of diagnosis throughout their life. It therefore suggests a more public health intervention that can critically respond appropriately to this burden currently confronting people with hepatitis B in Ghana. We therefore, recommend integration of hepatitis B counselling (pre-test and post-test counselling) in the already existing HIV structures. Furthermore, it is also important as a country to draw lessons from the process used in the diagnosis of HIV particularly, in ensuring that people provide consent for being tested.

Abbreviation

HBV- Hepatitis B Virus; WHO-World Health Organisation

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Transcribed data cannot be shared since participants did not consent to this. However, they are with the authors to avoid possible identification of the quotations with any of the participants.

Authors Contributions

CAA conceptualised the study. CAA, FN, ESD designed the study and the interview guide. Data were collected by CAA. Data analysis was done by FN, ESD and CAA. Manuscript was critically reviewed by FN and ESD. All authors read and approved the final manuscript.

Competing Interest

The authors declare no competing interest

Consent for publication

Not applicable

Ethical Approval

Ethical clearance was obtained from Institutional Review Board of Noguchi Memorial Institute for Medical Research (Approval number NMIMR-IRB CPN 026/ 15-16). Permission was sought from the management of the data collection sites, and informed consent (written) was obtained from the participants.

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Supplementary file 1: Interview Guide

1. Please tell me about yourself
 - a. Age?
 - b. Sex?
 - c. Occupation?
 - d. Tribe?
 - e. Education?
 - f. Your marital status?
 - g. How many children do you have?
 - h. When were you first diagnosed hepatitis B positive?
 - i. How were you diagnosed?
2. Can you share with me how you felt when you were first informed that you were positive for hepatitis B? (Probe).
3. Ever since you got to know your hepatitis status, how do you perceive life in general? (Probe). Describe
4. Can you share with me if your positive status has any psychological effect on your personal life? (Probe). Give example
5. With all the issues you have discussed with me, can you share with me some strategies you have put in place in coping with the infection? (Probe). Give example

COREQ (CONsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the inter view or focus group?	
Duration	21	What was the duration of the inter views or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.